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'A Story in Itself': The Artist-Researcher and Performative Dissemination

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> *Chairs are set out in a neat circle. Chatter from the care home flickers in and out of earshot. A snippet of music plays. A teacup clinks. Participants hesitantly find their way to a chair as a warm smile greets them. Slowly, gently, the dancing begins…*

Beyond the Walls is a piece of artist-research choreographed and performed by dance artists Lucy Evans and Stella Howard from Trinity Laban Conservatoire of Music and Dance (Trinity Laban). Featuring live music and performed in the round, this 45-minute choreographic work endeavours to conjure the lived experience of being present at a care home arts programme for people with dementia. Drawing from the artists' experience, this chapter argues the need for an authentic research methodology to match the language and experiential voice of the arts. We investigate the value of this innovative project by drawing attention to the kinaesthetic understanding at the heart of dance, and its capacity to animate the idea of 'embodied selfhood' (Kontos 2004) and provoke alternative modes of empathy.

The Project

From 2012-2015, reminiscence arts charity Age Exchange[1] worked closely with researchers from Royal Holloway University of London to investigate the impact of their work in care homes on participants with dementia, deploying a range of qualitative and quantitative research methods. RADIQL (Reminiscence Arts and Dementia Impact on Quality of Life) was initially a three-year programme supported by Guy's & St Thomas' Charity and focused on twelve

[1] Age Exchange uses Reminiscence Arts for the creative exploration of memories. Their approach is person-centred and they 'believe that focusing on the individual, their stories and experiences is the cornerstone of reducing loneliness and improving wellbeing' (Age Exchange n.d.).

residential or continuing care units in Southwark and Lambeth in South London[2]. During this time, Age Exchange delivered weekly Reminiscence Arts activities for participants with dementia using creativity linked with personal history 'in order to enrich caring relationships in the present' (Age Exchange n.d.).[3]

A key finding and experience of RADIQL was a new way of looking at and understanding the practice of Reminiscence Arts. In working with older people with mid to higher levels of dementia, Age Exchange explored new approaches that were dependent on embodied and sense memory rather than a spoken reminiscence narrative. Furthermore, Age Exchange wanted to explore an alternative approach to demonstrating the impact of their work to funders and other parties in a more dynamic and immersive way than the customary end-of-project report. This encouraged Age Exchange to partner with Trinity Laban. The charity commissioned two dance artists, Lucy and Stella, to explore in more depth the potential of the body to express lived experience and imagination, and to develop a performance piece that would encapsulate the impact of Age Exchange's practice. Created in 2016, *Beyond the Walls* sought to reimagine the creation and dissemination of an arts in health project evaluation as a living, breathing, multi-sensory encounter.

Lucy and Stella spent three months embedded in one of Age Exchange's care home arts programmes, acting as 'participant-observers'. With extensive experience in participatory arts, Lucy and Stella reflected on their roles as observers and their relation to the group. From an ethical perspective, they were conscious of the need to immerse themselves in the physical and mental space of the arts activities so not to counter the inclusive goal of participation. As researchers, they placed themselves as assistants to the Age Exchange facilitators during the arts activities and would then collate their observations and thoughts afterwards. While merely observing the activities may have alienated Lucy and Stella from the group and generated less insight into how participants and group dynamics changed over time, their participation instead afforded a lived experience that facilitated a personal connection to the care home residents.

Lucy and Stella's participant observation was an interactive process. Early on, they noted everything they witnessed, experienced and sensed, such as residents' mannerisms, the effect of music on rhythmic quality of movement responses to Age Exchange's activity, how care home

[2] The final report see Royal Holloway University of London (2015).
[3] For more information about the programme see *RADIQL: A guide* (Age Exchange 2015).

staff moved through the space, and details of the physical environment. Such an approach enabled data to be collected without constraint or prior assumptions. Over time, themes in the data started to emerge which allowed Lucy and Stella's observations to become narrower and more refined. Three core themes emerged that Lucy and Stella explored in their studio research: relatedness, environment and histories.

An ongoing consideration was how it was possible to reinterpret their lived experience as material for performance, in a different space, at a different time and with different bodies. From the outset of the devising process, Lucy and Stella were clear their choreography would not seek to directly mimic the movements of the programme participants. And while some marked changes were observed in individual participants across the 12 weeks, the choreography is focused primarily on exploring and communicating the emerging relationship between facilitator and participant, and the different forms of engagement unlocked by Age Exchange's work. From here, they devised a piece of choreography that distilled and expressed their findings. The resulting 45-minute work is a playful, moving and uplifting piece of choreography featuring live and recorded sound alongside audience interaction. *Beyond the Walls* tells the story of the participatory project that Lucy and Stella observed, but reframed in an imaginative, largely abstracted way. The piece focuses on the nuance and minutiae of what 'engagement' might mean in this context, with a strong emphasis on the value of non-verbal exchanges. *Beyond the Walls* was performed to critical acclaim around the UK, including performances at arts venues for key stakeholders comprising Arts Council representatives, researchers from Royal Holloway University of London, and Age Exchange staff, and performances at academic conferences.

Art-based Research

Art-based research is defined by Maggi Savin-Baden and Katherine Wimpenny as research 'that uses the arts, in the broadest sense, to explore, understand and represent human action and experience' (2014: 1). Art-based research emerged from the interaction between art and social sciences and has its roots in the 1970s shift in the social sciences that saw researchers adopting more diverse forms of inquiry, including narrative and hermeneutic approaches which were in turn reflexive and often grounded in arts practices (Finley 2005). Such research practice is based on the understanding that the arts can promote autonomy, activate the senses, express complex feelings and help individuals see and think differently (Chilton and Leavy 2014: 403).

While art-based enquiry remains something of an emergent paradigm, the approach continues to gain prominence around the globe, sparking conversations about what precisely constitutes 'knowledge', the value of alternative methods of data representation, and the role of empathy in recognising something about the experience of others (see Finley 2005; Irwin and de Cosson 2004; Hesse-Biber and Leavy 2006; Barrett and Bolt 2007; Knowles and Cole 2008; Liamputtong and Rumbold 2008). The importance of finding appropriate ways to disseminate research findings for arts in health projects is particularly critical.

Art scholars Gioia Chilton and Patricia Leavy have argued persuasively that the 'intersubjective realities' inherent in art participation are difficult to convey through 'standard methods' of research dissemination (2014: 407). More performative modes of data representation can lead to what arts education scholar Elliot Eisner calls 'productive ambiguity' where

> the material presented is more evocative than denotative, and in its evocation, it generates insight and invites attention to complexity. Unlike the traditional ideal of conventional research, some alternative forms of data representation result in less closure and more plausible interpretations of the meanings of the situation. (1997: 8)

This chapter articulates dance as one such alternative form of research and evaluation. Counter to the ongoing instrumentalism found to underpin many arts in health studies, the authors are keen to embrace the capacity of such 'evocation' to highlight and explore the nuance and complexity of arts participation, both through the research process itself and through the performative dissemination of findings.

Two Theories of Engagement: Embodied Selfhood and Empathy

Leavy's work highlights the 'moral or ethical imperative for researchers to use available resources, including creating new and trans-disciplinary approaches to research, in order to serve the communities in which we are enmeshed' (2015: 22). In this vein, the use of dance as a medium through which to explore the qualities of participant engagement and subsequently to disseminate these findings among wider audiences seems particularly apposite when

investigating an arts programme working with people with dementia, many of whom are non-verbal. We here briefly explore how the concepts of 'embodied selfhood' and different modes of empathy (including the notion of 'kinaesthetic empathy') helped to unpick the specific value of this project.

Dance artist Stella Howard immersed in Reminiscence Arts activities as a participant observer in a care home, 2016. Courtesy of Roswitha Chesher and Trinity Laban Conservatoire of Music and Dance.

Researcher Pia Kontos has challenged the mind/body dualism that tends to underlie the assumed 'loss of selfhood' found in current constructions of Alzheimer's disease (2004). Instead, Kontos asserts that selfhood is embodied and that it is, in turn, characterized by an 'observable coherence' in the body which, citing Wacquant, never loses its 'generative, creative capacity to understand' (Wacquant 1992: 20 in Kontos 2006: 208). As such, while people with dementia may become non-verbal, scholars have come to emphasize how they are without question still 'situated embodied agents who demonstrate bodily autonomy and embodied selfhood' (Hughes 2014: 89). With this in mind, exploring how the body and movement might express 'selfhood' was crucial to *Beyond the Walls*. Stella recalls an incident during an Age Exchange workshop when one participant was given a paintbrush,

> but instead of painting with it, she would conduct with it in the space and she'd stamp with it and she'd brush with it and she'd flick with it and at times she would sweep clear the table… and it might have seemed like pent-up aggression, and I think for some of the residents it scared them… but I don't think it was aggression. I think it was just a force of emotion, and for Lucy and me, it was a beautiful piece of dance.

What might have been interpreted as unwanted aggression was here understood as a form of expressive intent or 'gestural significance', as Kontos terms it (2004: 840). In turn, Lucy and Stella incorporated aspects of these movements into their choreography, conveying to audiences something of the vital and expressive qualities of these gestures through performance. Indeed, for Stella, the people she encountered were each telling

> personal stories – not in a literal way, but in the sense of the physical experience of the body. There is a story of the body [and] it could be a verbal story, or it could be the story of the *way* somebody painted. There was one particular lady who painted with real detail, and actually that is an expression and a story in itself.

Lucy and Stella's expertise in reading movement enabled them to attend to and explore the significance of gesture, including the smallest movement of the fingers or facial expression of participants in the later stages of living with dementia. This was transposed into performance, not through mimicking actions but through recognising the span of movement possibilities in size, quality, and intention. For example, in performance Lucy and Stella could be seen moving through the space and around audience members but also drawing attention to small movements of the foot or hand by making this the dominant focus for participant and audience alike.

Central to Lucy and Stella's time in the care home was an attempt to develop an intense form of physical empathy between themselves and the participants, a process the artists referred to as 'reading' stories through the body. The notion of empathy as an integral, 'heightened' element within dance practice (between dancers, and between dancers and audience) is supported by a wide range of literature (see Fraenkel 1983; Foster 2010; Reynolds and Reason 2012; Ribeiro and Fonseca 2011; Samaritter and Payne 2013). In this vein, a particular form of

empathetic exchange known as 'kinaesthetic empathy' was central to *Beyond the Walls*, both in the process of 'data collection' and development of the choreography, but also during the public performance of this dance work as an act of dissemination.

Kinaesthetic empathy describes the ability to experience empathy merely by observing the movements of another human being (Reynolds and Reason, 2012) and the concept was central to Lucy and Stella's observational work in the care home: it was only through their own lived, empathetic encounters with the Age Exchange programme that they gathered the data that underpinned their devising process. Lucy recalls how later in the rehearsal studio, improvisations around participant movement that the artists had observed would sometimes jolt them into what felt like sudden and unexpectedly acute physical and 'empathetic' connections with participants:

> We were doing an improvisation about not being engaged – not responding – and I remember walking backwards while Stella was lying on the floor [and in the way] … I interpreted the rules of this improvisation as being that I just had to keep trying to walk, even though it became impossible. In my mind, I didn't want to solve that problem because the point was "you're not engaging and thinking and then responding, you're just doing what you're doing". I had this sudden insight into how that felt – and that it was something specific actually, like it wasn't frustration and "move out the way" or it wasn't anger, it wasn't even upset, it was just this vacuum of having a single purpose and not being able to use or enjoy or ask anything of anyone or anything around you. It was an isolating experience. And I think that was one of the project's strongest moments.

This empathetic encounter was at first driven by what philosopher and cognitive scientist Evan Thompson terms 'imaginative transportation', where a subject seeks to 'mentally adopt the other's perspective by exchanging places with the other in imagination' (2007: 397). However, through enacting this scene physically, Lucy found herself seemingly inhabiting, for an instant, a world beyond her own, and in doing so, finding fresh insight through a form of 'reflexive embodied empathy' (Finlay 2005). The improvisation, used as a tool for creative research, allowed a variety of thoughts, feelings and influences to come together, contributing to the

intention and performance quality of choreography, which fed into both the devising process and the final performance. This approach was crucial because Lucy and Stella's performative selves were not intended to be characterised by a particular role of person they observed in the care home setting, rather to be shaped by the nature and quality of relationship.

Scholars have highlighted how kinaesthetic knowledge and understanding are at the heart of applied theatre practice where participatory performance is used to 'effect' change through 'affecting' participants and audience members (Nicholson 2005; Thompson 2009). Subsequent to the empathetic encounters experienced by the artists, *Beyond the Walls* invited audience members to experience a certain kinaesthetic empathy too. Through the performance's in-the-round setting and a variety of interactive exchanges choreographed throughout the piece, audience members are offered a 'lived experience' of the care home setting. This interactive and immersive performance endeavoured to embed its audiences in a heightened reimagining of the Age Exchange workshop environment, in all its intimate, complex sensibility. Embracing the subjectivity of the artistic encounter, the audience could then experience something of the programme's challenges, triumphs and, critically, its emotional core.

The care home setting had a huge impact on Lucy and Stella, from witnessing a constant flow of people coming in and out of the space to the general ambience. The choreography is particularly powerful in conjuring the atmosphere of being physically present at a reminiscence arts session. The work's opening, for instance, seeks to recreate (for the audience) the mixed sensations that participants may have experienced at the start of a session: audience members enter the space to a recorded soundtrack composed of lightly distorted sounds – fragments of music, conversation fluttering by, doors opening and closing – and is invited then to take their seats in-the-round, while the dance artists move quietly about behind them. Stella notes, 'we decided to perform in the round, with the audience seated in a circle to evoke the feeling of being a participant […] that sense of uncomfortableness, of multiple things happening, of not quite knowing what's going on.' The piece is thus not just about the 'end result' of a participatory programme, it is also about inviting audiences to experience something of the sensation of taking part.

At the centre of the piece are a set of white cardboard suitcases (see Figure 2).[4] These boxes are stacked, pushed, thrown and, on occasion, passed around various audience members. Lucy explains how Age Exchange

> often use suitcases in their practice, and this eventually morphed into the idea of us using cardboard suitcases – so that we could build structures, spread them out, open them, take things out of them. The suitcases let us construct and deconstruct and reconstruct the space… so that we could chart a space for the audience that was constantly changing.

Lucy and Stella made an artistic choice not to use the suitcases as they had been used in the Age exchange workshops, rather they were a vehicle for interpersonal connection and represented the relationship between artists and participants. The suitcases also held a strong link to the participants' stories and were used to denote a journey, a past.

Lucy Evans, Beyond the Walls, 2016. Performance. Trinity Laban Conservatoire of Music and Dance, Studio Theatre. Courtesy of Roswitha Chesher and Trinity Laban Conservatoire of Music.

[4] Age Exchange is an art reminiscence charity, that uses historical artefacts and props as memory triggers to help unlock stories in people with dementia. Many of these props are stored in old suitcases that once opened hold a specific place and time, such as a trip to the pier in the 1920's.

The suitcases sometimes feature in the choreography as physical obstacles and at other moments they stand as receptacles for precious memories. At the close of the work, the suitcases are opened and passed among the audience members to explore, revealing a magical array of sensory 'prompts', from lavender stems to autumn leaves to a box of 'After Eights' chocolates that the audience is invited to eat. Lucy and Stella note how stimulating the senses through different objects is a key technique used by the Age Exchange facilitators. Prompts which awaken smell, touch and taste are used to change the energy of the space, to evoke memories, to spark a sense of play, and to refresh interaction and engagement. For example, Lucy and Stella noted how introducing feathers as props in the sessions inspired movement in some participants who immediately started playing and catching the feathers, while feathers were used to gently stroke and tickle participants who showed no obvious movement responses to encourage sensation and physical response. Stella recalls 'seeing one resident, who had severely constricted movement, take deeper breaths and gently move her head. This was a positive engaging reaction for her.' So, Lucy and Stella's choreography here seeks to offer a taste of this positive, playful approach.

Application in Other Contexts

The two underpinning theories of engagement outlined above – acknowledging the 'embodied selfhood' of each participant and exploring alternative modes of empathy among artist-researchers and audiences – proved central to the workings of *Beyond the Walls*. These theories also demonstrate how using a performative art form such as dance within research and evaluation methodology can be used productively across the participatory arts more widely, as well as in other health and care environments and across the medical humanities.

As arts researchers Kate Wakeling and Jonathan Owen Clark set out in their paper contesting conventional theories and measures of well-being in arts in health programmes, the kind of 'meaning' that participants so often draw from various forms of arts participation (and not just when participants are non-verbal) is 'embodied' (2015). As philosopher Mark Johnson outlines, 'embodied meaning' stands in contrast to established 'conceptual-propositional theory' of meaning (2007: 10): if we take a non-dualistic view of mind and body and, hence, experience of the world, we find that it is not just language that is the sole bearer of meaning, but rather meaning arises out of our lived interactions and sensory experiences. It is thus incumbent on researchers to explore how the immediate experiential and embodied properties of arts activities

can more accurately be captured and expressed, and to accept that language, underpinned as it is by such 'conceptual-propositional' theories of meaning, may yet delimit researchers' capacities to probe and express the nuance and complexity of art participation.

Crucial to the success of a project such as *Beyond the Walls* is recognising the identity and expertise of the artists as researchers in their own right. The approach discussed in this chapter positions Lucy and Stella as participant-observers immersed in a reminiscence art programme for the preliminary stages of data gathering, not just creatively 'translating' existing data (i.e. that which may been generated through other methods). A dance artist's ability to 'read' what is happening in any room, to sense and embody the lived experiences of others, and then 're-tell' said experience in an inclusive, experiential and sensitive way is thus potentially valuable for a wide range of organisations who wish to express the holistic value of their work, particularly when there is a need to advocate for such work among key stakeholders (i.e. project partners, participants and their families, and the academic community). As Leavy suggests, there is much knowledge to be mined, and understanding to gain when using the arts as a tool:

> Given the limitation I found with traditional academic articles, I turned to an expressive art […] I was able to deliver the content, layer more themes, portray composite characters sensitively, create empathetic understandings, promote self-reflection in readers, create longer lasting learning experiences for readers, and most importantly get the work out to the public. (2015: 2)

Ethical Considerations and Challenges

In her ethnographic reflections, Kontos describes **'**the complex inter-relationship between primordial and social characteristics of the body, all of which reside below the threshold of cognition, are grounded in the pre-reflective level of experience, and are manifest primarily in corporeal ways' (2004: 837). As Julian Hughes describes,

> It is through my body that I have the words that I do. And its meaning is not just a matter of knowledge and cognitive function, rather my human body, as a body-subject, also creates an affective, emotional and expressive space. (2014: 81)

Lucy and Stella's embodied knowledge proved particularly valuable here and their informed way of 'reading' physical gesture and their acute empathic awareness could in a sense 'give voice' to individual experience. However, we cannot escape the subjectivity and contextual 'lens' of these dance artists. It is necessary to interrogate, therefore, how appropriate it is for two women in their thirties to employ such methodologies with a group of diverse older adults living with dementia, and potential problems arise in how gestures are 'read', how the complexity of meaning is grasped, and what the implications are of imposing layers of meaning over a participant's physical expression. Arguably, the expertise of dance artists who have longstanding experience in participatory work places them in a favourable position to interpret these movements, and such an approach that explores movement 'on its own terms' may still be more ethically appropriate than many other forms of evaluation and research investigating the impact of the arts on non-verbal participants.

The *Beyond the Walls* project specifically draws attention to other, less overt, forms of communication which continue to operate when verbal communication is no longer possible. However, the ethical question of consent is an important consideration, particularly when the cognitive function of care home participants has declined to the point where 'understanding' is perceived as being too challenging, and agreeing consent thus falls to a family member or assigned individual. *Beyond the Walls* raises certain ethical questions about how the 'voices' of participants are included in a research and evaluation process in which they are the subjects. Lucy and Stella discussed the appropriateness of putting the participants on stage, or in using older dancers to perform the work. In the end, they decided to perform the work themselves with the intention of drawing people into the experience of Age Exchange's work and its benefits to the participants involved. As the choreography developed, it became clear that the intended audience was not the care home residents that they had observed. Reflecting on this, Lucy and Stella recognise that sections of the work could feel insensitive, too abstract, or alienating to care home residents and that the choreography would need editing if performed in the care home setting. Nevertheless, there is also a moral or ethical imperative to ensure that evaluation and research methods for arts in health programmes do not exclude the same people placed at the heart of the work itself (Leavy 2015: 22). As Hughes asserts:

> The stories of people with severe dementia are full of meaning, which we may or may not share. But to ignore the possibility of doing so – to fail to see their actions as significant and to fail to see our own responses as potentially conveying meaning – would be to undermine our, and their standing as situated human beings (2014: 90).

Thus, in such a context where consent proved problematic, the importance of nonetheless including the 'voices' of individuals who are more often than not excluded from such research perhaps outweighs other ethical problems of the chosen methodology.

Conclusion

Beyond the Walls is an innovative piece of research because of the creative approach and performative dissemination of findings. While a traditional report or academic paper may have been seen only by a particular kind of audience, *Beyond the Walls* offers diverse audiences a rich and personal insight into the inner workings of a participatory arts programme, and sparks new conversations about how we might more effectively express and share the value and meaning of arts participation. The case for an 'alternative' authentic methodology speaks to the need for an ethical, person-centred approach to research, evaluation and dissemination. The act of taking part can offer participants a rich, complex and meaningful encounter. In turn, it is perhaps only by marrying modes of engagement particular to the expressive arts with more conventional research methodologies that we can access and communicate the transformational nature of taking part itself.

The rise in arts in health initiatives, including the increasing availability of arts on prescription (see Bungay and Clift 2010), necessitates a corresponding rise in evidence and continued consideration of what constitutes appropriate, ethical, and humane methods of research, evaluation and dissemination. The discussion of *Beyond the Walls* in this chapter identifies the value of investing in an innovative, imaginative and non-reductive approach to investigating and disseminating the outcomes of an arts programme, with potential for widespread application with far-reaching implications. Far from being limited to the language of health stakeholders, such a project demonstrates an accessible and democratised approach that

communicates directly with those engaged with participatory arts programmes: the artists, the participants, carers, family members, and the broader arts in health community.

While we understand the call for 'robust' quantitative evidence that validates the impact of the arts in our financially-straitened times, we believe there is also a powerful need for evidence that communicates the value of art *on its own terms*. When audiences reflect on their experiences of *Beyond the Walls*, they talk about connecting to the emotional heart of Age Exchange's work. This, for us, is what 'impact' is all about, and this is why we are excited at the potential of such projects as *Beyond the Walls* to help us reimagine the creation and dissemination of research and evaluation, bringing alive something of the splendid colour, mess and emotion of arts participation.

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